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Title

Does electromagnetic hypersensitivity originate from nocebo responses? Indications from a qualitative study

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Abstract

Idiopathic Environmental Intolerance attributed to Electromagnetic Fields (IEI-EMF) is a condition in which symptoms are attributed to electromagnetic fields (EMF) exposure. As electrohypersensitive (EHS) people have repeatedly been observed, during provocation trials, to report symptoms following perceived rather than actual exposure, the hypothesis has been put forward that IEI-EMF originates from psychological mechanisms, especially nocebo responses. This paper examines this hypothesis, using data from a qualitative study aimed at understanding how EHS people come to regard themselves as such. Forty self-diagnosed EHS people were interviewed. A typified model of their attribution process was then elaborated, inductively, from their narratives. This model is linear and composed of seven stages: (1) onset of symptoms; (2) failure to find a solution; (3) discovery of EHS; (4) gathering of information about EHS; (5) implicit appearance of conviction; (6) experimentation; (7) conscious acceptance of conviction. Overall, the symptoms appear before the subjects start questioning the effects of EMF on their health, which is not consistent with the hypothesis that IEI-EMF originates from nocebo responses to perceived EMF exposure. However, such responses might occur at the sixth stage of the process, potentially reinforcing the attribution. It remains possible that some cases of IEI-EMF originate from other psychological mechanisms.

Keywords

Idiopathic Environmental Intolerance, IEI-EMF, Illness Narratives, Attribution Process, Causal Reasoning

Introduction

Idiopathic Environmental Intolerance attributed to Electromagnetic Fields (IEI-EMF) is a condition attributed to electromagnetic fields (EMF) exposure. Its onset seems relatively recent: the first cases were reported in Sweden in the beginning of the 1990s [Bergqvist and Vogel, 1997]. In France, where this study was conducted, the earliest testimonies of people claiming to suffer from “electro-hypersensitivity” (EHS) were published in 2006. Since the number of purported sufferers has increased gradually (by July 30, 2015, 1,218 people had registered with the national support group “E.H.S. Entraide”). In France still, EHS started to receive media coverage in 2007 [Chateauraynaud and Debaz, 2010], and is a growing concern for health and industrial authorities.

The combination of several observations suggests a psychogenic origin for this condition. From a clinical point of view, the physical symptoms attributed to EMF exposure, either in daily life or in experimental contexts, are both various and non-specific: the most commonly reported are fatigue, headaches, cognitive difficulties, memory loss, insomnia, cutaneous rashes, and pain in numerous locations [Marc-Vergnes, 2010; Hagström et al., 2013; Baliatsas et al., 2015]. No physiopathological mechanism has been proven to be involved, notably because a recurring association between the onset of symptoms (or of objectively measured physiological changes) among EHS subjects and their exposure to EMF has not been observed in experimental settings [Röösli, 2008; Rubin et al., 2010; Rubin et al., 2011]. Besides, the devices typically blamed by these subjects (e.g., mobile phones and base stations, and WiFi routers) are not known for triggering adverse biological effects in their standard conditions of use (that is, at levels of exposure too low for thermal effects to occur) [SCENIHR, 2015]. People labeling themselves EHS also seem to experience higher levels of stress, anxiety, depression and somatization than the average person [Johansson et al., 2010].

All these observations indicate that IEI-EMF might be classified among functional somatic syndromes (FSS) [Barsky and Borus, 1999], or symptom-based conditions [Hyams, 1998]. They also explain why it remains an essentially self-reported condition, lacking an objective and unambiguous case-definition [Baliatsas et al., 2012]. In this paper, the term EHS is used to refer to

this subjective aspect of IEI-EMF (conversely, the term IEI-EMF is employed – as it was defined during the World Health Organization 2004 Prague workshop – to designate the illness that may account for the symptoms experienced by subjectively EHS people [Hansson Mild et al., 2006]).

Additional results bring forward the more specific hypothesis of an involvement of nocebo responses in this condition: the observation of a consistent correlation between the number and intensity of the symptoms reported by EHS subjects in provocation trials, and perceived exposure [Ofstedal et al., 2007; Eltiti et al., 2015]. Nocebo response is a term originally crafted to designate the occurrence, after the administering of a medication, of symptoms or adverse physiological changes that cannot be explained by its pharmacological properties, and are therefore attributed to the patients' expectations or unconscious reactions. Its existence has been demonstrated beyond doubt in the context of clinical trials [Barsky et al., 2002]. Moreover, several well-established physiological mechanisms can explain its functioning: the stress response [Chrousos and Gold, 1992], panic attacks [Staudenmayer, 1998], or conditioning and learning [Benedetti et al., 2003] – though there is no apparent consensus on the exact mechanism involved [Jakovljevic, 2014]. The nocebo response thus appears as a convincing explanation of EHS subjects' reactions in experimental settings, and to a certain extent, of the symptoms they experience in daily life. Indeed, they tend to express more concern over pollution and toxic agents in their environment than healthy controls [Rubin et al., 2008], and some of the personality traits they display (notably anxiety and somatization) are regarded as enhancing nocebo reactivity [Barsky et al., 2002].

These elements lead to the understanding of IEI-EMF as the result of a vicious circle, in which negative expectations about the health effects of EMF exposure increase the awareness of EMF sources in the environment, as well as the monitoring of bodily sensations, bringing nocebo-prone people to discover or amplify symptoms when they feel they are exposed. This confirms their expectations, and fuels a cycle of nocebo responses that operates until and after they label themselves EHS [Szemerszky et al., 2010; Witthöft and Rubin, 2013]. But how does this cycle start? Are media warnings about EMF health effects sufficient, as these authors assert, when they

meet with personality traits enhancing placebo responsiveness? Do they deserve to be described as “polluting minds” [Szemerszky et al., 2010] and “self-fulfilling” [Witthöft and Rubin, 2013]? If not, are other psychological mechanisms involved in the formation of the symptoms experienced by EHS people? Despite the growing body of research devoted to IEI-EMF, virtually no observational data is available to test these hypothesis, and little is known about the series of experiences and events that lead EHS people to perceive themselves as such. This paper presents the results of a qualitative study, which was carried out to understand this phenomenon. It formulates a typified model of the underlying attribution process, and discusses whether it fits with the hypothesis of an involvement of placebo responses, or other psychological mechanisms, in the genesis of IEI-EMF.

Materials and methods

No method has been proposed nor validated to examine the attribution process of EHS people. This study was therefore conducted with an inductive approach, and must be considered explanatory.

Participants

For a first approach, the most straightforward method appeared to focus on people genuinely convinced of their condition. To ensure this was the case, two inclusion criteria were used: the claim to suffer from EHS, evidently, and the adjustment of one’s lifestyle accordingly (e.g., getting rid of one’s electronic devices, shielding one’s home from EMF, avoiding places deemed exposed, etc.). They proved largely redundant, leading only to the exclusion of a few people from the study: people who considered themselves lightly sensitive to specific devices, but had not modified their lifestyle, and denied they were EHS. They were close relations of EHS people, or activists campaigning against “electromagnetic pollution,” who appeared cautious rather than sick. They likely correspond to the mild form of IEI-EMF observed by some authors [Rubin et al., 2008; Johansson et al., 2010].

The participants (11 men and 29 women, mean age 51 ± 11 years) were recruited by means of an announcement sent on several mailing lists of EMF-sensitive people, direct requests during EHS support groups meetings, and by word of mouth through personal networks. The sample was diversified as much as possible in terms of social and illness features. Its size ($n = 40$) was determined using the saturation principle [Mason, 2010]. The demographic characteristics of the subjects are presented in Table 1. The symptoms they attribute to EMF exposure are detailed in Table 2, and the number of symptoms they reported in Table 3. The perceived sources of exposure are listed in Table 4.

Interviews

An essential aspect of coping with a chronic illness is the elaboration of an “illness narrative”: a structured story that arranges the memories and experiences of the ill person in a meaningful way, giving a sense to his or her suffering, and allowing to convey it to others [Kleinman, 1988]. The challenge is therefore to reconstitute the original course of events (what can be called the “factual biography”) from these “narrative reconstructions” [Williams, 1984].

For that purpose, a two-steps method of interviewing was used. The subjects were initially presented with a broad question (“How did things happen for you?”), to which they could answer freely, for as long as they wished. Then specific questions were asked following a detailed interview guide, about (1) their symptoms, (2) their ways of coping with them, (3) how they came to attribute them to EMF exposure, (4) their perceived effects on their social relationships, and (5) their main social characteristics. By enabling comparison between the narrative first told by the subjects and the specific answers they give afterward, this method facilitates the detection of retrospective shifts of memories (the most significant that was observed being a tendency to overlook the active part they took in the construction of EHS as a convincing explanation of their predicament).

The common tricks of the qualitative investigator [Becker, 1998] were employed to obtain accurate information (e.g., rephrasing the questions, repeating them at different times in the

interviews, saving the sensitive ones for the end, asking “how?” rather than “why?”, etc.). At the same time, great care was taken not to suggest answers. The questions were formulated in an open and neutral way, as in the following examples: “Can you describe precisely what you feel when you’re exposed? What convinced you that EMF exposure was responsible for your symptoms? Do you ever doubt it? How do you distinguish between the symptoms triggered by EMF exposure, and those resulting from other causes?” When the subjects appeared hesitant, they were asked about the precision of their memories and their degree of certainty.

Lastly, precautions were taken against the desirability bias. To create a climate of trust, and avoid the participants being stressed by the confrontation with an unknown environment, the interviews were conducted in venues of their choice (mostly their homes). The investigator was careful about turning off all electronic devices prior to approaching each of them. He wore no perfume nor freshly washed clothes in case they were sensitive to chemicals, and displayed an understanding and benevolent attitude. Overall, the subjects responded very positively to these efforts. They regularly thanked him for offering them an opportunity to speak unashamedly of their condition, and willingly assisted in the reconstitution of their factual biographies.

Detailed information was thus collected with a relatively low risk of inaccuracy. The interviews were conducted in rural and urban areas of France between February 2012 and September 2013. Their average duration was 143 min. They were consistently recorded, and transcribed for analysis.

Data analysis

It quickly appeared that diagnosing themselves EHS had not been obvious for the subjects, but was rather the outcome of long and distressing trajectories, involving many dimensions of their lived experience (somatic perceptions, emotions, thoughts, behaviors, interactions with others, etc.). Gradually, a few typical circumstances all of them had gone through, seemingly in the same order, became apparent. The analysis was then directed toward understanding how these were connected, that is, how the subjects had passed from one set of circumstances to the next, and so forth, until they became truly convinced they were EHS. It was conducted under three assumptions: (1) that

their factual biographies could be analyzed as following a logical sequence (the attribution process); (2) that the progression of this sequence could be accounted for by bringing together all significant dimensions of the subjects' experience at each of its stages; and (3) that some elements of their experience might not appear explicitly in their discourses, but might be inferred from their behaviors and thoughts.

A single synthetic model of the attribution process was thus obtained. It was then cross-checked for consistency with each of the subjects' factual biographies, even though it does not aim at describing them: it focuses on their most determinant features, so as to explain their relations and the forms they take. Hence it is a pure type, in the Weberian sense. This method is more ambitious than the one consisting in listing the main themes of the subjects' discourses, as applied by Nettleton et al. [2005] to patients with medically unexplained symptoms (MUS), or Dumit [2006] to sufferers of chronic fatigue syndrome (CFS) and multiple chemical sensitivity (MCS): it presents more risk, but can yield results having a better explaining power.

Results

The typified attribution process underlying the subjects' factual biographies is linear and composed of seven main stages. Each is illustrated with significant excerpts from the interviews.

Stage 1 – onset of symptoms

Disturbing or incapacitating symptoms appear and develop until they become unmanageable. This might happen either progressively (over the course of several years) or suddenly (within a few weeks), but always results in a “biographical disruption” [Bury, 1982] (i.e., an inability to fulfill one's professional and/or domestic duties), which reveals the abnormality of the symptoms.

“To be honest, I used to be hyperactive. And then suddenly, boom! nothing. Well it wasn't that sudden, it took two years. I grew weaker and weaker, I could do fewer and fewer things, I couldn't knit I couldn't read. [...] By the time it ended in 2009, I could do absolutely nothing

but work. I had been compelled to employ a cleaning lady because I couldn't even do the housework." [Woman, aged 59]

"Then gradually, at the office [...] I could not figure out what people were asking me. I felt confused, as if my eyes were going back into the orbits, as if I had a constant strain in my eyes. And twinges of pain, the skull squeezed – in short, a whole set was beginning to put itself in place, and I was starting to feel very ill, I mean truly ill, as if I was being affected by something, and I could not understand what was happening." [Woman, aged 58]

Stage 2 – failure to get a (medical) solution

The subjects seek treatment for their ailment from general practitioners, medical specialists or alternative therapists – most of the time from them all, because none of the treatments offered prove effective in the long term. So they fail to restore the normality of their situation. Furthermore, they also fail to get a conventional diagnosis, which means they are denied the possibility of legitimately endorsing the sick role, and make the abnormality of their situation socially acceptable (some subjects managed to get diagnosed with a “contested illness” [Conrad and Barker, 2010] like fibromyalgia (6 subjects) or late Lyme disease (5 subjects), which proved of little avail as in France, these conditions are not generally recognized by medical authorities and social services). This leaves them feeling profoundly distressed and stigmatized, as most patients with MUS [Nettleton et al., 2005], or CFS and MCS sufferers [Dumit, 2006]. The length of this stage varies greatly also.

"I found myself on the ground. Because of chronic pain. Something infernal. The doctors groped around for three years, and for three years they believed I was going to die. They looked for everything: a cancer, AIDS, AIDS-related illnesses, lots of viruses, tropical diseases, and so on. For five years I didn't get a diagnosis, no one could tell me what I was suffering from. [...] To begin with, you go and see your physician, because when you fall ill the only person you're thinking of consulting is your physician. You have no choice, you've been raised that way, you'll never think of turning to alternative medicines. Then I don't know, after three or four

years, you say: 'okay, medicine, allopathy is powerless.' You begin to turn to alternative medicines. You go to a homeopath, you go to an iridologist, you go to a magnetotherapist, you go and see this you go and see that. Well as it turned out, it's the magnetotherapist who did me the best." [Man, aged 46]

Stage 3 – discovery of EHS

The previous stage comes to an end when the subjects happen to learn about EHS, in which they catch a glimpse of an explanation for their ailment. This encounter can occur through different media: a radio show, a newspaper article (usually from the local or militant press), a talk with friends or relatives – but very rarely the Internet. It implies the same content: the testimony of an alleged EHS sufferer, in which they recognize themselves (*"what he was telling, that was me, that was what I was living"*). This moment is experienced as a genuine revelation. It goes along with a vertiginous questioning (*"what if EHS is what I'm suffering from?"*), that expresses a psychological tension between the hope of a relief (having finally identified the disease that is affecting them) and the fear of a disappointment (having identified the wrong disease).

"For me it was at work. I was on the computer, and a colleague told me – because they could see I was breaking down. They saw me, I was about to freak out. And so they told me: 'yeah, you know, I've seen a TV show, heard of, there are people who are hypersensitive to radio-waves. Could you have it?' Then we looked on the Internet, and voilà, we saw... Well at that time, in 2006, there wasn't much. There were a couple of testimonies, and it's true that when looking at the symptoms, when comparing the symptoms, they were exactly those I had. Insomnia, headaches, difficulty in concentrating, dizziness... Exactly the aches that... So, that's how I reached that conclusion." [Woman, aged 45]

Stage 4 – gathering of information about EHS

The third stage is very brief, since the subjects immediately begin to gather information on EHS, in a rather compulsive manner. They consult the Internet first, then solicit support groups, small but active associations campaigning against wireless communications, and companies selling EMF protection devices. This information typically concerns the other sufferers' symptoms and the devices to which they attribute them. Its analysis causes a shift of the emotional conflict, i.e., a displacement of the focus of relief (*"I suffer from a real disease, I'm not crazy, it's not all in my head"*) and still more, of the focus of fear (in anticipation of the multiple constraints associated with this condition, revealed by catastrophic testimonies: *"how am I going to live?"*). This stage is short but extremely intense, the subjects tending to devote all their available time to their investigation (*"I needed to know"*). It also proves emotionally taxing.

"Like everyone, I started looking on the Internet. Which is... very good and horrible at the same time. As soon as you suspect a disease or something, that's it. Without delving into the details, you imagine everything you see, everything you read, and so on. And it's true that afterwards, fear makes you feel unable to cope with that thing." [Woman, aged 37]

Stage 5 – implicit appearance of conviction

The conviction that they are EHS appears in the subjects' minds, but seemingly escapes their awareness: they start reasoning as if they were sensitive to EMF, while consciously doubting they are (as observed in the next stage). Arguably, this happens after relief has (even temporarily) prevailed over fear: a quarter of the subjects (10) have emphasized how important it had been to succeed in alleviating their symptoms the first time they knowingly attempted to reduce their exposure to EMF.

“Now I don’t have my pains anymore, so I’m reassured, because I know that... it is possible to recover, there are remedies.” [Man, aged 50]

“What convinced you, was to see that the advice you were given were effective?

– *They were very, very effective.*

– Did you notice the difference immediately?

– *Well, actually, I never tried again to sleep with the fuses on. [...] Even so it made me feel really strange, I was telling myself: ‘what’s this delirium, turning off one’s bedroom’s fuse to sleep? What have I fallen into?’ And well, I saw it was working, that’s it.”* [Man, aged 39]

For 9 subjects, this implicit conviction has taken the paradoxical form of a deliberate and violent rejection of the diagnostic of EHS (*“I don’t want this illness, it’s too bad!”*).

“Do you want me to talk about the doubts one can have? And especially the fears, when you say: No, I don’t want to be electrosensitive! It’s the others who emit too much. And there are places where you feel good, so you are not electrosensitive. Then you see there are more and more places where you feel ill.” [Man, aged 54]

Stage 6 – experimentation

The subjects initiate an active verification procedure, conducting small experiments to confirm the existence of a relationship between their health state and their electromagnetic environment. Their realization requires them to learn several things:

1. Which devices emit EMF. Initially the subjects only know (at best) about mobile phones and base stations, and WiFi routers; but soon enough they discover that cordless phones, fluorescent lamps, computers, TV sets, smoke detectors, etc., also radiate (considering indistinctly radio frequency and extremely low frequency sources).
2. How to identify these devices in their environment: either by direct visual observation (e.g., spotting antennas on the buildings close to their homes); indirectly by using various EMF

sensors (e.g., radio frequency power meters, low-level magnetic fields strength meters, or indicators for electric fields in the ELF range – preferably those which provide visual or acoustic indications); or even vicariously by looking for informants (e.g., technicians in their workplace about WiFi networks, or neighbors about cordless phones in their homes).

3. How to protect themselves from EMF (e.g., by turning some devices off, sleeping under a shielded canopy, wearing shielded garments, etc.).

The subjects thus become able to link their symptoms to EMF exposure, in a distinctly adversarial manner. For instance, they do not admit any threshold in their sensitivity: every exposure they manage to identify, whatever its source, power or duration, is regarded as a plausible cause of their symptoms. Similarly, when they find themselves unable to identify a source of exposure, they tend to discard the possibility that such a source is absent. This remarkable imperviousness to disproof justifies to regard them as implicitly convinced that they are sensitive to EMF.

At the end of this sixth stage, the diagnosis of EHS appears as a persuasive explanation for their ailment. It also proves somewhat effective in coping with it, not least because it provides them with a sense of control.

“Actually, I was walking in the street, I was feeling it, I was raising my head, there was an antenna. [...] Or I was in a room with someone, I felt it, and two seconds later his mobile phone rang. So gradually I discovered, I was telling myself: ‘damn, I’m a sensor.’” [Woman, aged 41]

“Now I notice that my body is more receptive than my EMF sensor, so even if the sensor shows nothing, the body may perceive. When this happens, I need to move a little with the sensor, and I quickly find the pollution source. So far, I’ve never had a WiFi sensation, without finding a WiFi nearby. That is to say I’ve never dreamed it. If my sensor detects nothing, I go out and five meters away I find one.” [Woman, aged 55]

“I’m taking a music lesson and I warn people that I faint with... with cell phones. And then I really get the proof it wasn’t psychosomatic, because I faint nonetheless, even if everybody was warned. [...] So I learn, after fainting, that there was indeed someone making a phone call in

the next room: 'yes, so as not to disturb you.' So if I could feel the waves through the walls, that was the proof [that I was EHS]." [Woman, aged 57]

Stage 7 – conscious acceptance of conviction

The emotional conflict having now been resolved, the conviction that they are EHS becomes bearable for the subjects, and reaches the conscious level. The ability to demonstrate its independence from their will, stemming from the experiments they have conducted, likely plays a decisive role in this process (as indicated by their tendency, in their illness narratives, to overlook the desire they had to find an explanation for their ailment: *"I was really skeptical but was forced to believe"*). The subjects now regarding themselves as EHS sufferers, start knowingly adapting their lifestyle, rewriting their personal stories to make them coherent with their new belief system (i.e., constructing their illness narratives), and sometimes campaigning for the official recognition of their condition.

"First you need, not to convince yourself, but to accept that that's it. [...] That's why I was doing blind tests and all, because you do everything you can to say to yourself: 'well, no.'"
[Man, aged 51]

"What EHS sufferers are often reproached with is their obsession about it. But once you have understood – you have rebuilt the puzzle and understood that all your miscellaneous symptoms were due to it, once you recognize the headaches, which I tell you are no sinusitis, are no viruses, are really very specific – you know it's that." [Woman, aged 33]

This goes along with a transformation of their attitude towards somatic perceptions: they cease putting their reality in doubt when faced with dissonant elements (e.g., if they fail to identify a source of exposure after the onset of symptoms).

“The sensor detects one second after me. And there are places where it’s not sensitive enough, and I feel too many things, and it shows nothing. Moreover, when I turn it on it hurts me, I feel it. So it must concentrate, I think, the waves around it. [...] I have it just in case, to check for people, but as for me, I prefer to see things by feeling myself.

– Do you trust yourself more than the sensor?

– *Exactly. Furthermore because afterwards, you need to know how to interpret the sensor data. I prefer to interpret my feeling. And even if it’s a bad place and I feel good, why not, I mean, it’s the body which answers, which speaks.”* [Woman, aged 52]

Consequently, the subjects did not seem to differ by their degree of certainty (though this is difficult to assess comparatively). They were not more or less convinced they were EHS, but rather convinced they were more or less EHS, and in different ways. In their view, as the investigator has regularly been told, *“there are as many sensitivities as hypersensitive people.”*

Discussion

The most significant feature of the subjects’ typified attribution process is that the symptoms onset before the environment is suspected, and EMF exposure is interpreted as noxious and held responsible for them. How long before is difficult to quantify because the subjects did not always remember exactly when their symptoms appeared (which is unavoidable when it dates back several years). But there is no doubt they were already feeling sick (stage 1) – because they had sought, and failed to obtain, medical assistance (stage 2) – when they started questioning the effects of EMF in their environment on their health (stage 4).

Furthermore, only 5 subjects knew precisely what EMF were at the time their symptoms began (they were working as teachers or engineers, and had studied physics). Twelve other subjects had been cautioned in the past against specific EMF-emitting devices: mobile phones and WiFi routers mostly, either by a relative, an alternative therapist they were consulting, or a news report. However, they did not remember having been warned against EMF health effects in general, and

did not start feeling concerned until they fell ill and discovered the existence of EHS (stage 3). The 23 remaining subjects had never heard of EMF before reaching the same stage in the attribution process. Arguably, had they been initially convinced of the harmfulness of EMF exposure, they would not have felt such an urge to gather information about it (stage 4), nor to establish so attentively its correlation with their symptoms, so as to prove to themselves they are indeed EHS (stage 6).

Therefore, it seems highly implausible that their ailment originates from adverse expectations related to EMF. The vicious circle of IEI-EMF, assuming the corresponding model is correct, is unlikely to be triggered by media (or personal) warnings, even in conjunction with personality traits enhancing nocebo responsiveness: rather, it adds to preexisting conditions, resulting precisely from their sufferers' struggle to understand them. This does not imply, however, that nocebo responses are not involved in the genesis of IEI-EMF.

Nocebo and placebo responses in the attribution process

First, they are likely to occur at one point of the attribution process: when the subjects start scrutinizing their electromagnetic environment, especially if they resort to EMF sensors (stage 6). This behavior leads them to observe the ubiquity of EMF, which arouses negative expectations and anxiety. Remarkably, a few subjects (3) seemed aware of this reaction, relating how they committed themselves to abandoning their scrutinizing behavior due precisely to the worry they were causing themselves.

“As soon as I realized what it was, there was a psychological effect. Things got a little worse, because I was identifying [the exposures].” [Man, aged 39]

“The more I observed [my environment] to avoid exposing myself, to avoid fainting, the more sensitive I was.” [Woman, aged 57]

Similarly, placebo responses might intervene slightly earlier in the attribution process, the first time the subjects try to relieve their symptoms through reducing EMF exposure. Doing so with high hopes and expectations, they meet with instantaneous success (*“I turned my WiFi router off and immediately, all my symptoms disappeared”*) – while the following attempts, whose outcome is taken for granted, generally prove less fortunate. The attribution process thus has strong emotional implications (stage 5 and 7), which might promote nocebo and placebo responses and have somatic consequences (inducing new symptoms, aggravating the existing ones, or alleviating them). These might in turn contribute to the subjects’ progression through the attribution process, promoting the perception of EHS as a convincing explanation of their ailment – although it does not seem likely for all of them.

The case for unconscious conditioning and “technological stress”

A possibility remains for nocebo responses to account for the genesis of the ailment attributed to EMF: that they do not involve conscious expectations related to EMF, but rather unconscious processes as part of a conditioning mechanism. Such a hypothesis was originally put forward to account for the symptoms attributed to visual display units (VDU) in occupational settings [Arnetz and Wiholm, 1997]. It builds upon the observation that the use of new technological devices is frequently a source of stress, especially for motivated workers who regard their job as stimulating, but feel they lack the appropriate skills. This “technostress” might cause them to regularly experience symptoms, and get conditioned to their work environment. However, they would focus on these new devices, or other elements in their workplaces, when searching for an explanation of their ailment – and find it in the EMF they generate. They would then start reacting adversely to other devices identified as emitting EMF, even outside of their workplace, because of conscious expectations triggering nocebo responses. They would eventually develop a severe form of IEI-EMF, and label themselves EHS.

This hypothesis is supported by the observation that people attributing symptoms to VDU tend to display higher levels of technostress than their colleagues, and that people reporting a sensitivity to

mobile phones are also more likely to use their own for work [Rubin et al., 2008]. In this study, one participant recounted that his symptoms began at work, and that he managed to connect them to EMF exposure several months later, when he started working with a wireless modem. Another participant declared his symptoms originated in an occupational use of computers. None of them mentioned difficulties in using these devices (they were both technology enthusiasts), or work-related stress. Five other subjects reported they were experiencing such stress when their symptoms first appeared, but linked them with EMF exposure through devices in their homes.

Thus, the hypothesis of unconscious conditioning somewhat fits with the factual biographies of a few subjects, indicating that some cases of IEI-EMF might originate from technological stress. However, if it explains the origin of the symptoms, it does not account for their attribution to EMF, and cannot be substituted to the process presented above.

Implications for the understanding of IEI-EMF

Overall, these observations suggest that EHS people would be better conceived as patients suffering from MUS, which they come to attribute to EMF exposure. This attribution allows them, firstly to make sense of those symptoms, then to act upon them: it is a means of empowering themselves against their ailment. This perspective has significant implications for the understanding of IEI-EMF.

First, the responsibility of media warnings about EMF health effects in the development of this condition should not be overestimated. They certainly affect, and likely shape, the perception of EMF risk [Burgess, 2004]. But to its sufferers, IEI-EMF does not initially appear as a risk, but as an explanation for their ailment. Furthermore, media warnings hardly contribute to the credibility of this explanation compared to the sharing of testimonies with other EHS people, the discovery of information on how to cope with EMF exposure, and personal experiments. Thus, their effect is essentially to make EHS widely available as a potential diagnosis for people suffering from MUS.

Second, people with IEI-EMF should be distinguished from “modern health worriers” (MHW) [Petrie et al., 2001], whose concerns make them more likely to react adversely during provocation

trials, but who have no need nor reason to diagnose themselves EHS, since they do not necessarily suffer from persistent, incapacitating, and “medically unexplainable” symptoms. Alternatively, the presence of such symptoms might characterize a severe form of IEI-EMF, while MHW could be regarded as presenting its mild form (there is little empirical indication that these two forms constitute a homogeneous clinical entity, and should be analyzed identically).

A third implication is that people with IEI-EMF should also be distinguished from IEI sufferers. These attribute symptoms to chemicals in their environment, which they seem to identify through their sense of smell. Many have been observed, in experimental settings, responding to olfactory stimuli [Das-Munshi et al., 2006]. This makes it rather straightforward for them to connect their symptoms to their environment: perceiving chemicals directly, they do not need to reveal their presence retrospectively, for instance by using sensors, as EHS people do. Consequently, the involvement of unconscious conditioning mechanisms in the formation of their symptoms appears more likely [Meulders et al., 2010] – especially since many cases of IEI have been reported to occur after a massive exposure to some chemical substance [Staudenmayer, 1998].

Fourthly, regarding IEI-EMF as consisting in the attribution of MUS to EMF exposure incites to apprehend it less as a homogeneous clinical entity, than as a label covering miscellaneous ailments. Various causes should then be considered for the symptoms originally experienced by EHS people: technostress and unconscious conditioning, as seen above, undiagnosed chronic illnesses or psychiatric conditions, dysregulation of the autonomic nervous system [Sandström et al., 2003] potentially amplifying the responsiveness to sensory stimuli [Nordin et al., 2014], actual sensitivity to EMF, etc.

Limitations

The first limitation of this study derives from its qualitative nature. The data is only as accurate as the subjects’ perceptions and memories, and the eventuality cannot be excluded that some bias have not been adequately controlled for during the interviews. Besides, the non-implementation of a

conventional method of sampling precludes estimating the representativeness of the sample. Care should thus be taken before generalizing the results.

More specifically, a second set of restrictions stems from the design of this study. The inclusion criteria as well as the recruitment strategy might have led to the enrollment of participants with a rather severe form of IEI-EMF [Van Dongen et al., 2014], and there is no indication that the genesis of its mild form can be accounted for by the proposed model of the attribution process. The functioning of this model may also be affected by the psychological characteristics of the subjects, which were not objectively assessed. Moreover, its efficiency is difficult to evaluate, for the investigator was unable to discover people having either seriously thought they might be EHS and concluded they were not, or having regarded themselves as EHS and subsequently ceased to. This is not surprising as such people would predictably leave the EHS network, thus becoming difficult to identify. Still, their cases would be interesting to document. Finally, as this paper is focused on the genesis of IEI-EMF, it only deals with the factual biographies of EHS people until they become convinced they are EHS; it does not address what happens after, and does not reflect the diversity of personal situations in which EHS people can actually be found.

Conclusion

The results of this study are not consistent with the hypothesis that severe IEI-EMF is a condition originating from placebo responses to perceived EMF exposure, even though it is likely to be aggravated, after its onset, by a vicious circle of such responses. These results do not indicate either, that other psychological mechanisms are systematically involved in the formation of the symptoms initially experienced by EHS people (i.e., before they come to regard themselves as such). Rather, they suggest to consider EHS as a label applied by some MUS sufferers to their ailment, in their struggle to make it emotionally and practically manageable. This arguably justifies the clinical and experimental elusiveness of IEI-EMF, and the ongoing inability to define it objectively, which are likely accentuated by the generic nature of the attribution process. The fact that it functions with

virtually every type of symptoms might explain why the efforts to reduce the subjective aspects of IEI-EMF have hardly made it a less perplexing condition.

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References

- Arnetz BB, Wiholm C. 1997. Technological stress: psychophysiological symptoms in modern offices. *J Psychosom Res* 43:35–42.
- Baliatsas C, Kamp IV, Lebrete E, Rubin GJ. 2012. Idiopathic environmental intolerance attributed to electromagnetic fields (IEI-EMF): A systematic review of identifying criteria. *BMC Public Health* 12:643.
- Baliatsas C, Bolte J, Yzermans J, Kelfkens G, Hooiveld M, Lebrete E, van Kamp I. 2015. Actual and perceived exposure to electromagnetic fields and non-specific physical symptoms: An epidemiological study based on self-reported data and electronic medical records. *Int J Hyg Environ Health* 218:331–344.
- Barsky AJ, Borus JF. 1999. Functional somatic syndromes. *Ann Intern Med* 130:910–921.
- Barsky AJ, Saintfort R, Rogers MP, Borus JF. 2002. Nonspecific medication side effects and the nocebo phenomenon. *JAMA* 287:622–627.
- Becker HS. 1998. *Tricks of the Trade: How to Think about Your Research While You're Doing It*. Chicago (IL): University of Chicago Press.
- Benedetti F, Pollo A, Lopiano L, Lanotte M, Vighetti S, Rainero I. 2003. Conscious expectation and unconscious conditioning in analgesic, motor, and hormonal placebo/nocebo responses. *J Neurosci* 23:4315–4323.

- Bergqvist U, Vogel E., eds. 1997. Possible health implications of subjective symptoms and electromagnetic fields. A report prepared by a European group of experts for the European Commission, DG V. Arbete och Hälsa 19:1–45. Solna (Sweden): Swedish National Institute for Working Life.
- Burgess A. 2004. Cellular Phones, Public Fears, and a Culture of Precaution. Cambridge (UK): Cambridge University Press.
- Bury M. 1982. Chronic illness as biographical disruption. *Sociol Health Illn* 4:167–182.
- Chateauraynaud F, Debaz J. 2010. Le partage de l'hypersensible : le surgissement des électrohypersensibles dans l'espace public. *Sci Soc Santé* 28:5–5.
- Chrousos GP, Gold PW. 1992. The concepts of stress and stress system disorders. Overview of physical and behavioral homeostasis. *JAMA* 267:1244–1252.
- Conrad P, Barker KK. 2010. The social construction of illness. Key insights and policy implications. *J Health Soc Behav* 51:S67–S79.
- Das-Munshi J, Rubin GJ, Wessely S. 2006. Multiple chemical sensitivities: A systematic review of provocation studies. *J Allergy Clin Immunol* 118:1257–1264.
- Dumit J. 2006. Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses. *Soc Sci Med* 62:577–590.
- Eltiti S, Wallace D, Russo R, Fox E. 2015. Aggregated data from two double-blind base station provocation studies comparing individuals with idiopathic environmental intolerance with attribution to electromagnetic fields and controls. *Bioelectromagnetics* 36:96–107.
- Hagström M, Auranen J, Ekman R. 2013. Electromagnetic hypersensitive Finns: Symptoms, perceived sources and treatments, a questionnaire study. *Pathophysiology* 20:117–122.
- Hansson Mild K, Repacholi M, van Deventer E, Ravazzani P, eds. 2006. Electromagnetic Hypersensitivity: Proceedings, International Workshop on EMF Hypersensitivity, Prague, Czech Republic, October 25-27, 2004. Geneva (Switzerland): WHO Press. p. 16

- Hyams KC. 1998. Developing case definitions for symptom-based conditions: the problem of specificity. *Epidemiol Rev* 20:148–156.
- Jakovljevic M. 2014. The placebo-nocebo response: controversies and challenges from clinical and research perspective. *Eur Neuropsychopharmacol* 24:333–341.
- Johansson A, Nordin S, Heiden M, Sandström M. 2010. Symptoms, personality traits, and stress in people with mobile phone-related symptoms and electromagnetic hypersensitivity. *J Psychosom Res* 68:37–45.
- Kleinman A. 1988. *The Illness Narratives: Suffering, Healing, And The Human Condition*. New York (NY): Basic books. pp. 49–51
- Marc-Vergnes J-P. 2010. Electromagnetic hypersensitivity: The opinion of an observer neurologist. *C R Phys* 11:564–575.
- Mason M. 2010. Sample size and saturation in PhD studies using qualitative interviews. *Forum Qual Soc Res* 11:Art. 8.
- Meulders A, Fannes S, Van Diest I, De Peuter S, Vansteenwegen D, Van den Bergh O. 2010. Resistance to extinction in an odor-20% CO₂ inhalation paradigm: further evidence for a symptom learning account of multiple chemical sensitivity. *J Psychosom Res* 68:47–56.
- Nettleton S, Watt I, O'Malley L, Duffey P. 2005. Understanding the narratives of people who live with medically unexplained illness. *Patient Educ Couns* 56:205–210.
- Nordin S, Neely G, Olsson D, Sandström M. 2014. Odor and noise intolerance in persons with self-reported electromagnetic hypersensitivity. *Int J Environ Res Public Health* 11:8794–8805.
- Oftedal G, Straume A, Johnsson A, Stovner LJ. 2007. Mobile phone headache: a double blind, sham-controlled provocation study. *Cephalalgia* 27:447–455.
- Petrie KJ, Sivertsen B, Hysing M, Broadbent E, Moss-Morris R, Eriksen HR, Ursin H. 2001. Thoroughly modern worries: the relationship of worries about modernity to reported symptoms, health and medical care utilization. *J Psychosom Res* 51:395–401.

- Röösli M. 2008. Radiofrequency electromagnetic field exposure and non-specific symptoms of ill health: a systematic review. *Environ Res* 107:277–287.
- Rubin GJ, Cleare AJ, Wessely S. 2008. Psychological factors associated with self-reported sensitivity to mobile phones. *J Psychosom Res* 64:1–9.
- Rubin GJ, Nieto-Hernandez R, Wessely S. 2010. Idiopathic environmental intolerance attributed to electromagnetic fields (formerly “electromagnetic hypersensitivity”): An updated systematic review of provocation studies. *Bioelectromagnetics* 31:1–11.
- Rubin GJ, Hillert L, Nieto-Hernandez R, van Rongen E, Oftedal G. 2011. Do people with idiopathic environmental intolerance attributed to electromagnetic fields display physiological effects when exposed to electromagnetic fields? A systematic review of provocation studies. *Bioelectromagnetics* 32:593–609.
- Sandström M, Lyskov E, Hörnsten R, Hansson Mild K, Wiklund U, Rask P, Klucharev V, Stenberg B, Bjerle P. 2003. Holter ECG monitoring in patients with perceived electrical hypersensitivity. *Int J Psychophysiol* 49:227–235.
- SCENIHR (Scientific Committee on Emerging and Newly Identified Health Risks). 2015. Opinion on Potential Health Effects of Exposure to Electromagnetic Fields (EMF). Luxembourg: The European Commission, DG Health and Food Safety.
- Staudenmayer H. 1998. *Environmental Illness: Myth and Reality*. Boca Raton (FL): CRC Press. pp. 137–172
- Szemerszky R, Köteles F, Lihi R, Bárdos G. 2010. Polluted places or polluted minds? An experimental sham-exposure study on background psychological factors of symptom formation in “Idiopathic Environmental Intolerance attributed to electromagnetic fields.” *Int J Hyg Environ Health* 213:387–394.
- Van Dongen D, Smid T, Timmermans DRM. 2014. Symptom attribution and risk perception in individuals with idiopathic environmental intolerance to electromagnetic fields and in the general population. *Perspect Public Health* 134:160–168.

Williams G. 1984. The genesis of chronic illness: narrative re-construction. *Sociol Health Illn* 6:175–200.

Witthöft M, Rubin GJ. 2013. Are media warnings about the adverse health effects of modern life self-fulfilling? An experimental study on idiopathic environmental intolerance attributed to electromagnetic fields (IEI-EMF). *J Psychosom Res* 74:206–212.

Table 1 – Demographic characteristics of interviewed subjects

Age		
	18-24	1
	25-34	1
	35-44	11
	45-54	11
	55-64	10
	65-74	6
	75+	0
	Mean	51 years
Gender		
	Male	11
	Female	29
Marital Status		
	Unmarried, living alone	14
	Unmarried, living together	10
	Married, living together	10
	Divorced / widowed	6
Occupational status		
	Retired	7
	Working / studying	22
	Incapacitated	5
	Unemployed	6
	Housewife / man	0
Time since self-diagnosis of EHS		
	6 months to 2 years	15
	2 to 4 years	11
	4 to 6 years	14
	Median	3 years
Have left their job and/or their home because of their condition		
	Yes	17
	No	23

Table 2: symptoms attributed to EMF exposure, by the number of subjects who reported them

Sleep problems	28
Headaches	25
Pain in various locations	25
Abnormal fatigue	20
Concentration problems	17
Tinnitus	14
Memory loss	13
Skin rashes	11
Dizziness	8
Cardiac arrhythmia	8
Speech problems	7
Digestive problems	7
General feeling of ill-being	5
Nausea	5
Other symptoms	21

Table 3: number of reported symptoms, by the number of subjects

Low (4 symptoms or less)	14
Medium (5 to 7 symptoms)	17
High (8 symptoms or more)	9

Table 4: perceived sources of exposure, by the number of subjects who mentioned them

WiFi routers	34
Mobile phone base stations	28
Mobile phones	24
Digital Cordless Phones (DECT)	20
Electric home appliances	18
Fluorescent lamps	9
Computers (system units)	8
Screens (computer displays and TV sets)	6
Cars	4
Other sources	7